



#### General

#### Title

Palliative care: mean score on the "Socio-Cultural Atmosphere" dimension on the Quality from the Patient's Perspective Instrument Specific to Palliative Care (QPP-PC).

## Source(s)

Sandsdalen T, Rystedt I, GrÃ, ndahl VA, Hov R, HÃ, ye S, Wilde-Larsson B. Patients' perceptions of palliative care: adaptation of the Quality from the Patient's Perspective instrument for use in palliative care, and description of patients' perceptions of care received. BMC Palliat Care. 2015 Nov 2;14:54. PubMed

#### Measure Domain

#### Primary Measure Domain

Clinical Quality Measures: Patient Experience

## Secondary Measure Domain

Does not apply to this measure

## **Brief Abstract**

## Description

This measure is used to assess the mean scores on both the subjective importance (SI) and the perceived reality (PR) scales for the "Socio-Cultural Atmosphere" dimension on the Quality from the Patient's Perspective Instrument Specific to Palliative Care (QPP-PC).

The QPP-PC Instrument consists of 52 items including 4 dimensions with 12 factors (49 items) and 3 single items.

Patients answered each item in two ways. First, patients scored their opinions of the quality of actual care received, PR, related to the sentence "This is what I experience..." (e.g., personnel are respectful to me). Then patients scored the SI of care aspects, related to the sentence "This is how important this is to me..." (e.g., personnel are respectful to me). A four-point Likert scale, ranging from 1 (do not agree at all) to 4 (fully agree), was used for PR, and for SI from 1 (of little or no importance) to 4 (of the very highest importance). A non-applicable alternative was available for both responses.

The "Socio-Cultural Atmosphere" dimension includes the following five factors (16 items):

Meaningfulness

The personnel support and assist me in living the rest of my life in a meaningful way:

Doctors

Nurses

Other personnel

Spiritual and Existential

The personnel support and assist me in tending to my spiritual and existential needs:

Doctors

Nurses

Other personnel

Relatives and Friends

My relatives:

And friends are treated with respect
Receive the best possible help, support and care
May participate in decisions about my care, according to my preferences

Continuity

I usually receive help from the same:

Doctor

Nurse

My care is determined by my own requests and needs rather than staff procedures

Planning and Cooperation

There is good planning of my:

Medical care

Nursing care

The personnel cooperate well

All the health and welfare services that I receive are well coordinated

#### Rationale

The need to have knowledge and evaluate the quality of palliative care is recognized both internationally and in Norway (Ministry of Health and Care Services, 2015; Grande, 2009; World Health Organization [WHO], 2004). Patients' perceptions of their care may be seen as one aspect of quality of care (Donabedian, 1980; WHO, 2006) and is considered important for development and improvement of palliative care (Grande, 2009; WHO, 2004; WHO, 2006; Singer, Martin, & Kelner, 1999; Ministry of Health and Care Services, "Future care," 2013; Ministry of Health and Care Services, "High quality," 2013). To gain such knowledge, validated instruments are needed, which should be tested in different settings and on patients with different illnesses (Mularski et al., 2007; Unroe & Meier, 2013).

The advantage of using existing instruments to measure patients' perspectives of palliative care quality is that they have been developed within a palliative care context, including patients' views in the development process. The importance of instruments with a foundation of a theoretical model of care

quality that is based on patients' perspectives and conceptions of the area can be found in the literature (van Campen et al., 1995), and ensures the measurement of all important aspects of care quality from the patients' perspectives. However, there is a lack of instruments explicitly founded on a theoretical model of care quality from patients' perspectives.

The Quality from the Patient's Perspective Instrument Specific to Palliative Care (QPP-PC) is based on a theoretical model of quality of care, and has its roots in patients' perspectives; this gives patients undergoing palliative care a voice when measuring and evaluating the quality of care. The advantage of the QPP-PC is that the instrument includes measures of both subjective importance and perceived reality of care. This is particularly valuable for guiding the improvement of palliative care at all levels.

#### Evidence for Rationale

Donabedian A. Explorations in quality assessment and monitoring. Vol. 1, The definition of quality and approaches to its assessments. Ann Arbor (MI): Health Administration Press; 1980. 163 p.

Grande G. Palliative care in hospice and hospital: time to put the spotlight on neglected areas of research. Palliat Med. 2009 Apr;23(3):187-9. PubMed

Ministry of Health and Care Services. [Future care. Report to the Storting (Norwegian Parliament) no. 29.]. Oslo (Norway): Ministry of Health and Care Services; 2013.

Ministry of Health and Care Services. [High quality - safe services - quality and patient safety in the Health and Care Services. Report to the Storting (Norwegian Parliament) no.10]. Oslo (Norway): Ministry of Health and Care Services; 2013.

Ministry of Health and Care Services. [Report on services to persons in need of palliative treatment and care towards the end of life - to bring life to the days. Report from the Norwegian Directorate of Health. Report no. IS-2278]. Oslo (Norway): Ministry of Health and Care Services; 2015.

Mularski RA, Dy SM, Shugarman LR, Wilkinson AM, Lynn J, Shekelle PG, Morton SC, Sun VC, Hughes RG, Hilton LK, Maglione M, Rhodes SL, Rolon C, Lorenz KA. A systematic review of measures of end-of-life care and its outcomes. Health Serv Res. 2007 Oct;42(5):1848-70. PubMed

Sandsdalen T, Rystedt I, GrÃ, ndahl VA, Hov R, HÃ, ye S, Wilde-Larsson B. Patients' perceptions of palliative care: adaptation of the Quality from the Patient's Perspective instrument for use in palliative care, and description of patients' perceptions of care received. BMC Palliat Care. 2015 Nov 2;14:54. PubMed

Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. JAMA. 1999 Jan 13;281(2):163-8. PubMed

Unroe KT, Meier DE. Research priorities in geriatric palliative care: policy initiatives. J Palliat Med. 2013 Dec;16(12):1503-8. PubMed

van Campen C, Sixma H, Friele RD, Kerssens JJ, Peters L. Quality of care and patient satisfaction: a review of measuring instruments. Med Care Res Rev. 1995 Mar;52(1):109-33. PubMed

World Health Organization (WHO). Quality of care: a process for making strategic choices in health systems. Geneva (Switzerland): World Health Organization (WHO); 2006. 38 p.

World Health Organization (WHO). The solid facts: palliative care. Geneva (Switzerland): World Health

#### Primary Health Components

Palliative care; patient experience; socio-cultural atmosphere; meaningfulness; spiritual and existential needs; relatives and friends; continuity; planning and cooperation

#### **Denominator Description**

Total number of items completed by patients in the "Socio-Cultural Atmosphere" dimension on the Quality from the Patient's Perspective Instrument Specific to Palliative Care (QPP-PC) (see the related "Denominator Inclusions/Exclusions" field)

#### **Numerator Description**

Patients' subjective importance (SI) and perceived reality (PR) responses to items in the "Socio-Cultural Atmosphere" dimension (see the related "Numerator Inclusions/Exclusions" field)

# Evidence Supporting the Measure

## Type of Evidence Supporting the Criterion of Quality for the Measure

A systematic review of the clinical research literature (e.g., Cochrane Review)

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

## Additional Information Supporting Need for the Measure

Unspecified

# **Extent of Measure Testing**

One way of assessing whether the Quality from the Patient's Perspective Instrument Specific to Palliative Care (QPP-PC) is a reliable and valid instrument is to measure the QPP-PC according to the criteria stated by van Campen et al. (1995): instruments should (1) be based on a theoretical foundation, (2) contain a subscale representing different aspects of quality of care, (3) be tested for reliability and validity, and (4) be feasible in large populations. In the developers' opinion, the QPP-PC meets these criteria.

The items in the QPP-PC still reflect all four dimensions of the theoretical model of quality of care derived from patients' perspectives, on which the Quality from the Patient's Perspective Instrument (QPP) is based. Sitzia (1999) elaborated on the validity assessment of instruments by stating that studies should provide results for content validity comprising strategies for item generation and content testing. Items in the QPP-PC were developed based on the perspective of patients receiving palliative care, ensuring that the items developed are perceived as relevant for these patients. The pilot test showed good face and content validity; this was supported by high patients' scores on the subjective importance (SI) scale for each dimension, factor and single item (see Table 4 in the original measure documentation), which was also the case at the level of the items (not reported). Consequently, this supported the content validity of the instrument (Stizia, 1999).

The construct validity (Sitzia, 1999) was evaluated by performing an explorative factor analysis using

principal component analysis (PCA), which showed a stable 12-factor solution for the SI and perceived reality (PR) scales, with most items correlating strongly with the factors. Compared with the original QPP, three new factors appeared: "Exhaustion," "Continuity" and "Planning and Cooperation." Although "Exhaustion" appeared as a new factor, this aspect of care has been present as items in the Medical-Technical Competence (MT) dimension of the previous QPP instrument (personal communications with the author Wilde-Larsson). Previous research supports continuity, and planning and cooperation are important for patients who receive palliative care (Sandsdalen et al., 2015; Heyland et al., "Defining priorities," 2010; Murray et al., 2002) and should be included in measures in palliative care (Mularski et al., 2007). Compared to existing instruments measuring palliative care quality from patients' perspectives (Miyashita et al., 2014; Lo et al., 2009; Heyland et al., "The development and validation," 2010; Engelberg et al., 2010; Sulmasy et al., 2002). QPP-PC consists of similar aspects of care. However, to the developers' knowledge, previous instruments do not cover all these aspects of care in one single instrument.

Two items correlated with factors that differed from the original version of the QPP. The item about waiting times was previously described as a factor belonging to the MT dimension; however, in this study this item correlated with items in the factor "Access to Help, Food and Equipment," placed in the Physical-Technical Conditions (PT) dimension. The item about individualized care was previously described as a factor belonging to "Routines." In this study, this item correlated with items in the factor "Continuity." By developing new items and testing these in a new context, new constructs of items may appear that could partly explain the differences experienced in this study. With regard to continuity, it is reasonable to think that receiving help from the same doctors and nurses influences individualized care, and these items may therefore be expected to correlate. These findings need to be supported by further studies; the developers suggest that further validation of the instrument be obtained by confirmatory factor analysis.

Reliability (Sitzia, 1999) was assessed by Cronbach's a, and values were greater than 0.7 for most factors and dimensions on both the PR and the SI scales, indicating good internal consistency ("Exploratory factor analysis," 2014). This is in line with previous studies using the QPP in other contexts (Holter et al., 2014). However, the factor "Access to Help, Food and Equipment," in the PT dimension, and the factor "Continuity" showed a values less than 0.7. This a value for the PT dimension is in line with previous studies using the QPP in the context of hospital care (Wilde Larsson & Larsson, 2002; Grøndahl et al., 2011). The a values are sensitive to the number of items, and low numbers may lead to low a values, which could possibly explain the results (Field, 2013). The factors "Spiritual and Existential" and "Meaningfulness" gained high a levels, which may be explained by the items within both of these factors being the same questions asked by different healthcare personnel.

## Evidence for Extent of Measure Testing

Engelberg RA, Downey L, Wenrich MD, Cline JD, Silvestri GA, Dotolo D, Nielsen EL, Curtis JR. Measuring the quality of end-of-life care. J Pain Symptom Manage. 2010 Jun;39(6):951-71. PubMed

Exploratory factor analysis. In: Hair JF, Black WC, Babin BJ, Anderson RE, editor(s). Multivariate data analysis, 7th Pearson New International Edition. Harlow (UK): Pearson; 2014.

Field A. Discovering statistics using SPSS. 4th ed. Los Angeles (CA): Sage; 2013.

 $Gr\tilde{A}_{,n}$ ndahl VA, Karlsson I, Hall-Lord ML, Appelgren J, Wilde-Larsson B. Quality of care from patients' perspective: impact of the combination of person-related and external objective care conditions. J Clin Nurs. 2011 Sep;20(17-18):2540-51. PubMed

Heyland DK, Cook DJ, Rocker GM, Dodek PM, Kutsogiannis DJ, Skrobik Y, Jiang X, Day AG, Cohen SR, Canadian Researchers at the End of Life Network (CARENET). Defining priorities for improving end-of-life care in Canada. CMAJ. 2010 Nov 9;182(16):E747-52. PubMed

Heyland DK, Cook DJ, Rocker GM, Dodek PM, Kutsogiannis DJ, Skrobik Y, Jiang X, Day AG, Cohen SR, Canadian Researchers at the End of Life Network. The development and validation of a novel questionnaire to measure patient and family satisfaction with end-of-life care: the Canadian Health Care Evaluation Project (CANHELP) Questionnaire. Palliat Med. 2010 Oct;24(7):682-95. PubMed

Holter H, Sandin-Boj $\tilde{A}$ ¶ AK, Gejervall AL, Wikland M, Wilde-Larsson B, Bergh C. Quality of care in an IVF programme from a patient's perspective: development of a validated instrument. Hum Reprod. 2014 Mar;29(3):534-47. PubMed

Lo C, Burman D, Hales S, Swami N, Rodin G, Zimmermann C. The FAMCARE-Patient scale: measuring satisfaction with care of outpatients with advanced cancer. Eur J Cancer. 2009 Dec;45(18):3182-8. [40 references] PubMed

Miyashita M, Wada M, Morita T, Ishida M, Onishi H, Tsuneto S, Shima Y. Care evaluation scale-patient version: measuring the quality of the structure and process of palliative care from the patient's perspective. J Pain Symptom Manage. 2014 Jul;48(1):110-8. PubMed

Mularski RA, Dy SM, Shugarman LR, Wilkinson AM, Lynn J, Shekelle PG, Morton SC, Sun VC, Hughes RG, Hilton LK, Maglione M, Rhodes SL, Rolon C, Lorenz KA. A systematic review of measures of end-of-life care and its outcomes. Health Serv Res. 2007 Oct;42(5):1848-70. PubMed

Murray SA, Boyd K, Kendall M, Worth A, Benton TF, Clausen H. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. BMJ. 2002 Oct 26;325(7370):929-32. PubMed

Sandsdalen T, Hov R, HÃ, ye S, Rystedt I, Wilde-Larsson B. Patients' preferences in palliative care: a systematic mixed studies review. Palliat Med. 2015 May;29(5):399-419. PubMed

Sandsdalen T, Rystedt I, GrÃ, ndahl VA, Hov R, HÃ, ye S, Wilde-Larsson B. Patients' perceptions of palliative care: adaptation of the Quality from the Patient's Perspective instrument for use in palliative care, and description of patients' perceptions of care received. BMC Palliat Care. 2015 Nov 2;14:54. PubMed

Sitzia J. How valid and reliable are patient satisfaction data? An analysis of 195 studies. Int J Qual Health Care. 1999 Aug;11(4):319-28. PubMed

Sulmasy DP, McIlvane JM, Pasley PM, Rahn M. A scale for measuring patient perceptions of the quality of end-of-life care and satisfaction with treatment: the reliability and validity of QUEST. J Pain Symptom Manage. 2002 Jun;23(6):458-70. PubMed

van Campen C, Sixma H, Friele RD, Kerssens JJ, Peters L. Quality of care and patient satisfaction: a review of measuring instruments. Med Care Res Rev. 1995 Mar;52(1):109-33. PubMed

Wilde Larsson B, Larsson G. Development of a short form of the Quality from the Patient's Perspective (QPP) questionnaire. J Clin Nurs. 2002 Sep;11(5):681-7. PubMed

## State of Use of the Measure

#### State of Use

Pilot testing

#### Current Use

not defined yet

# Application of the Measure in its Current Use

#### Measurement Setting

Home Care

Hospices

Skilled Nursing Facilities/Nursing Homes

Transition

## Type of Care Coordination

Coordination across provider teams/sites

Coordination within a provider team/site

## Professionals Involved in Delivery of Health Services

not defined yet

## Least Aggregated Level of Services Delivery Addressed

Single Health Care Delivery or Public Health Organizations

## Statement of Acceptable Minimum Sample Size

Specified

## Target Population Age

Adults

## Target Population Gender

Either male or female

# National Strategy for Quality Improvement in Health Care

# National Quality Strategy Aim

Better Care

## National Quality Strategy Priority

Effective Communication and Care Coordination Person- and Family-centered Care

# Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need

Living with Illness

**IOM Domain** 

Patient-centeredness

## Data Collection for the Measure

#### Case Finding Period

Unspecified

## Denominator Sampling Frame

Patients associated with provider

## Denominator (Index) Event or Characteristic

Clinical Condition

#### **Denominator Time Window**

not defined yet

## **Denominator Inclusions/Exclusions**

Inclusions

Total number of items completed by patients in the "Socio-Cultural Atmosphere" dimension on the Quality from the Patient's Perspective Instrument Specific to Palliative Care (QPP-PC)

Eligible patients should be included in a palliative care service or, if not, there should be documentation in the patients' charts indicating that they are in a late palliative phase. In addition, eligible patients should be personally aware that they are in a palliative phase (having a life-threatening illness) and that they received palliative care (as judged by the responsible registered nurse [RN]).

Exclusions

Unspecified

#### Exclusions/Exceptions

not defined yet

#### Numerator Inclusions/Exclusions

Inclusions

Patients' subjective importance (SI) and perceived reality (PR) responses to items in the "Socio-Cultural Atmosphere" dimension

Note:

Patients answered each item in two ways. First, patients scored their opinions of the quality of actual care received, PR, related to the sentence "This is what I experience..." (e.g., personnel are respectful to me). Then patients scored the SI of care aspects, related to the sentence "This is how important this is to me..." (e.g., personnel are respectful to me). A four-point Likert scale, ranging from 1 (do not agree at all) to 4 (fully agree), was used for PR, and for SI from 1 (of little or no importance) to 4 (of the very highest importance). A non-applicable alternative was available for both responses.

Since the Quality from the Patient's Perspective Instrument Specific to Palliative Care (QPP-PC) was developed to measure the care quality in a number of different settings and for patients with several different illnesses, "not applicable" responses will always be present. For the QPP-PC dimensions and factors, a mean value is calculated based on the individual participant's response to the remaining items in the respective dimension or factor. When participants respond "not applicable" to an item, a mean of the remaining responses in the respective variable substitutes the "not applicable" response. Since the "not applicable" response is coded together with missing observations, any missing observation is also substituted by a mean of the remaining responses in the respective variable.

Exclusions Unspecified

## Numerator Search Strategy

Fixed time period or point in time

#### **Data Source**

Patient/Individual survey

## Type of Health State

Does not apply to this measure

## Instruments Used and/or Associated with the Measure

Quality from the Patient's Perspective Instrument Specific to Palliative Care (QPP-PC)

# Computation of the Measure

## Measure Specifies Disaggregation

Measure is disaggregated into categories based on different definitions of the denominator and/or numerator

## Basis for Disaggregation

This measure is disaggregated based on the "Meaningfulness," "Spiritual and Existential," "Relatives and Friends," and "Continuity," and "Planning and Cooperation" factors within the "Socio-cultural Atmosphere"

dimension.

A mean value is calculated based on the individual patient's responses to the items in the respective factor.

#### Scoring

Composite/Scale

Mean/Median

## Interpretation of Score

Desired value is a higher score

## Allowance for Patient or Population Factors

not defined yet

## Standard of Comparison

not defined yet

# **Identifying Information**

## **Original Title**

Socio-cultural atmosphere.

#### Measure Collection Name

Quality from the Patient's Perspective Instrument Specific to Palliative Care (QPP-PC)

#### Submitter

Improveit Digital Solutions - For Profit Organization

# Developer

Sandsdalen, Tuva, MNS, CCRN, RNT; Wilde-Larsson, Bodil, PhD, RNT - Independent Author(s)

# Funding Source(s)

- · Hedmark University College
- Lovisenberg Diakonale Hospital

## Composition of the Group that Developed the Measure

- Tuva Sandsdalen, MNS, CCRN, RNT, Faculty of Public Health, Department of Health Studies, Inland Norway University of Applied Sciences
- Ingrid Rystedt, PhD, Faculty of Health, Science and Technology, Department of Health Science, Discipline of Nursing Science, Karlstad University
- Sevald Høye, PhD, RNT, Faculty of Public Health, Department of Health Studies, Inland Norway University of Applied Sciences
- Vigdis Abrahamsen Grøndahl, PhD, RNT, Faculty of Health and Social Studies, Østfold University College
- Reidun Hov, PhD, RNT, Faculty of Public Health, Department of Health Studies, Inland Norway University of Applied Sciences
- Bodil Wilde-Larsson, PhD, RNT, Faculty of Health, Science and Technology, Department of Health Science, Discipline of Nursing Science, Karlstad University, Sweden Faculty of Public Health, Department of Health Studies, Inland Norway University of Applied Sciences

#### Financial Disclosures/Other Potential Conflicts of Interest

The authors declare that they have no competing interests.

#### Adaptation

The Quality from the Patient's Perspective Instrument Specific to Palliative Care (QPP-PC) was adapted from the QPP instrument for use in palliative care contexts.

## Date of Most Current Version in NQMC

2015 Nov

#### Measure Maintenance

Unspecified

## Date of Next Anticipated Revision

Unspecified

#### Measure Status

This is the current release of the measure.

# Measure Availability

For more information, contact Improveit Digital Solutions, Stationsgatan 58, 30250 Halmstad, Sweden; Phone: + 46 35 22 70 50; E-mail: info@improveit.se; Web site: www.improveit.se/

## Companion Documents

The following is available:

Sandsdalen T, Grøndahl V, Hov R, Høye S, Rystedt I, Wilde-Larsson B. Patients' perceptions of palliative care quality in hospice inpatient care, hospice day care, palliative units in nursing homes, and home care: a cross-sectional study. BMC Palliat Care. 2016 Aug 24;15(1):79. Available from the BMC Palliative Care Web site

## **NQMC Status**

This NQMC summary was completed by ECRI Institute on February 15, 2017. The information was not verified by the measure developer.

## Copyright Statement

No copyright restrictions apply.

## Production

## Source(s)

Sandsdalen T, Rystedt I, GrÃ, ndahl VA, Hov R, HÃ, ye S, Wilde-Larsson B. Patients' perceptions of palliative care: adaptation of the Quality from the Patient's Perspective instrument for use in palliative care, and description of patients' perceptions of care received. BMC Palliat Care. 2015 Nov 2;14:54. PubMed

## Disclaimer

## **NQMC** Disclaimer

The National Quality Measures Clearinghouseâ,,¢ (NQMC) does not develop, produce, approve, or endorse the measures represented on this site.

All measures summarized by NQMC and hosted on our site are produced under the auspices of medical specialty societies, relevant professional associations, public and private organizations, other government agencies, health care organizations or plans, individuals, and similar entities.

Measures represented on the NQMC Web site are submitted by measure developers, and are screened solely to determine that they meet the NQMC Inclusion Criteria.

NQMC, AHRQ, and its contractor ECRI Institute make no warranties concerning the content or its reliability and/or validity of the quality measures and related materials represented on this site. Moreover, the views and opinions of developers or authors of measures represented on this site do not necessarily state or reflect those of NQMC, AHRQ, or its contractor, ECRI Institute, and inclusion or hosting of measures in NQMC may not be used for advertising or commercial endorsement purposes.

Readers with questions regarding measure content are directed to contact the measure developer.